

# The Coverage Priorities of Disabled Adult Medi-Cal Beneficiaries

Marion Danis, MD  
Marjorie Ginsburg, MPH  
Susan Dorr Goold, MD, MHSA, MA

*Abstract:* Medi-Cal, like other Medicaid programs around the U.S., has been pressed to cut its budget. We report the results of a project using the CHAT (Choosing Healthplans All Together) exercise, designed to ascertain the priorities of disabled adult Medi-Cal beneficiaries to inform any decisions regarding Medi-Cal benefits. Participants voiced greatest interest in maintaining a wide spectrum of benefits and access to a large pool of providers and were most willing to restrict pharmacy benefits. The resulting findings may be of value to legislators drafting Medicaid proposals that revise benefits for this vulnerable population.

*Key words:* Medicaid, insurance benefits, cost and benefits, social policy, health policy, consumer preference.

Medicaid programs are among the most important government programs, insuring care for 50 million poor and chronically ill individuals, yet they are threatened in nearly every state because their costs consume an expanding share of state budgets that encroaches on other crucial state programs. In the past four years, the number of recipients has grown by a third and costs have risen by 10% annually to more than \$300 billion dollars per year. Governors and state legislators are drafting proposals to drastically change programs and save costs as Congress intends to give states new flexibility to reduce or reconfigure benefits for Medicaid beneficiaries.<sup>1,2</sup> Strategies proposed to control the cost of Medicaid include measures to decrease enrollment, limit benefits and/or utilization, increase co-payments and/or decrease payments to providers. Changes in Medicaid programs are highly contentious, with a coalition of advocates for Medicaid beneficiaries, labor unions, and health care providers preparing to fight any significant cutbacks. Finding cost-controlling or even cost-cutting strategies that will be acceptable to Medicaid beneficiaries poses severe challenges. One way that may mitigate the contentious decision making

---

**MARION DANIS** is the Head of the Section on Ethics and Health Policy of the Department of Clinical Bioethics at the National Institutes of Health in Bethesda, Maryland and can be reached at [mdanis@nih.gov](mailto:mdanis@nih.gov). **MARJORIE GINSBURG** is Executive Director of Sacramento Healthcare Decisions in Rancho Cordova, California and **SUSAN DORR GOOLD** is Associate Professor of Internal Medicine and Health Management and Policy and Director of the Bioethics Program at the University of Michigan Medical School.

process in a way that respects the needs and values of the most vulnerable is to ensure that limited health care resources match the service and benefit priorities of those with the most at stake—Medicaid beneficiaries themselves. To accomplish this goal, we believe that beneficiaries' choices should be one element that goes into the priority setting process along with expert opinion as policy gets made.

Here we report an effort in California to ascertain the priorities of a particularly vulnerable group of Medi-Cal beneficiaries. To inform state legislators in anticipation of budgetary decisions, a project was designed to determine the priorities of disabled adults enrolled in the Medi-Cal program. Disabled adults constitute 14% of all Medi-Cal beneficiaries, but 37% of the total Medi-Cal budget.<sup>3</sup> This group could face the greatest risk of service or enrollment cutbacks from the state's redesign efforts. Furthermore, with the long-term nature of their needs, adult disabled beneficiaries are quite familiar with the range of services and nuances of the delivery system. For these reasons, we considered the adult disabled category of Medicaid beneficiaries a good source of information on priorities.

## Methods

**The CHAT exercise.** The project used Choosing Healthplans All Together (CHAT), a computer-based simulation exercise developed to engage individuals in the challenges of choosing health care benefits when choices exceed available resources (available on request from the authors or at [chat-info@umich.edu](mailto:chat-info@umich.edu)).<sup>4</sup> Projects in several states with a variety of participants, including commercially insured employees, Medicare beneficiaries, and the uninsured have been used to validate CHAT.<sup>5–7</sup>

In brief, CHAT sessions are led by a facilitator and include up to 12 participants who engage in 4 rounds of decision making in a 2–3 hour session. Participants use a decision board shaped like a pie chart on which health care benefits are configured around the board (Figure 1). Each benefit is offered at up to 3 tiers representing different levels of services, restrictions and/or co-payments. Participants are given a set of markers representing available resources (equivalent to a per-member-per-month allotment) to use to allocate resources among the benefits they prioritize.

During round 1, participants work individually to design a coverage plan for themselves. During round 2, participants work in groups of three. During round 3, all group participants deliberate together, under the direction of the group facilitator. Participants nominate, discuss, debate, and negotiate which categories are most important and why. When necessary, groups may vote to finalize their decisions. This round is audio-taped for later review. In round 4, participants again create a coverage plan for themselves to assess how the group process has altered individual choices. Participants complete a pre-exercise questionnaire to collect socio-demographic information and a post-exercise questionnaire to measure attitudes related to the exercise and policy questions.

**Tailoring the CHAT exercise for the Medi-Cal population.** For the purposes of this project, participants were instructed in round 1 that they would be making a plan for themselves for five years. In round 2 they created a coverage plan for all adult disabled Medi-Cal beneficiaries in their county. In round 3 participants were

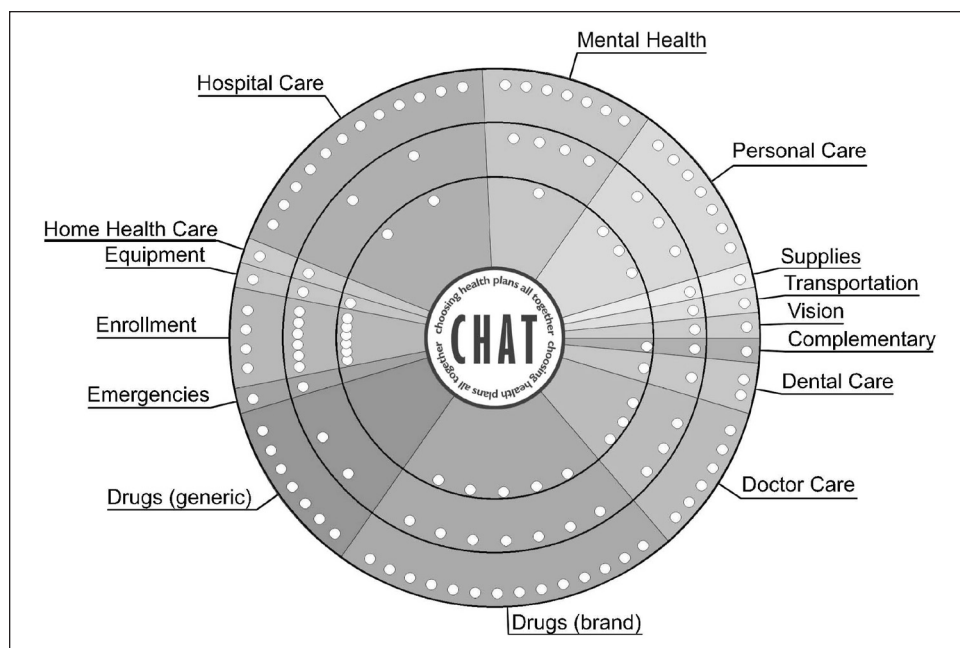


Figure 1. CHAT board for disabled adult Medi-Cal beneficiaries.

asked to design a benefits package for all adult disabled Medi-Cal beneficiaries in California.

An advisory committee of government personnel, health plan representatives, consumer advocates, and disability and Medi-Cal experts was convened to develop benefit options for the Medi-Cal CHAT exercise from which the participants would choose. The committee selected the CHAT categories used most often by adult disabled beneficiaries and developed alternative tiers of coverage (Appendix). One of the tiers offered in each benefit category described the current Medi-Cal benefit; other tiers offered lower or higher benefits. In addition to 14 service categories, such as Hospital Care and Equipment, there was an Enrollment category in which participants considered tightening eligibility as one way to preserve resources for augmenting service categories.

During the exercise, participants were assigned a premium allotment of \$540 per member per month, represented as 100 markers. Using medical claims data provided by the California Department of Health Services, the Lewin Group, a health care policy research group experienced with Medicaid population actuarial analysis in several states, estimated the actuarial cost for each category tier using Medicaid claims and cost data. The higher the tier, the more expensive the benefit, and the more markers needed to select it. Selection of the highest tiers (best benefits) offered on the CHAT board would have required a total of 123 markers. Choosing all services available in the Medi-Cal program at the time of the exercise required 114 markers. With 100 markers, participants could select 81% of the total set of options in the exercise (which represented 87% of existing Medi-Cal services).

**Pilot testing.** The exercise was pilot tested for use by disabled Medi-Cal population. Modest modifications were made to the CHAT descriptions after the pilot.

**Study participants.** Twelve sessions were conducted in April and May 2004, in 12 of the 57 counties in California selected to include Northern, Southern, and central parts of the state, as well as rural and urban counties. We picked this number of counties in order to complete data collection in a timely fashion to coincide with the state's Medi-Cal Re-Design process. Independent Living Centers were contacted and paid \$50 for each person they recruited for a CHAT session; participants were paid \$75 for their time. Participants met the following eligibility criteria: being a non-institutionalized disabled adult under age 65, receiving primary health care coverage from Medi-Cal, being literate in spoken and written English, having sufficient cognitive ability, and having basic computer experience. For participants who needed assistance, readers, computer assistants, and translators for the hearing-impaired provided help.

This project was approved by the Office of Human Subjects Research at the Clinical Center of the National Institutes of Health and exempted from Institutional Review Board review there, and was reviewed and approved by the University of Michigan IRBMED Institutional Review Board.

**Data analysis.** Choices of categories and tiers and responses to pre- and post-questionnaires were analyzed using descriptive statistics. McNemar's chi-square test was used to analyze differences between individual health care coverage choices (coverage either chosen at any level or not chosen at all) made during the first and fourth rounds of the exercise. Transcripts of group discussions were reviewed to identify and understand participants' reasons for benefit choices.

## Results

**Participant characteristics.** One hundred thirty-one disabled adults enrolled in Medi-Cal participated in 12 CHAT group exercises; most were single females with an average age of 47 years (Table 1). The types of disabilities they reported were wide-ranging; 31% reported multiple disabilities (Table 1). Nearly half the participants had been enrolled in Medi-Cal for over 10 years, and all but 4 had been enrolled for a least 1 year. Three quarters had seen a doctor at least 6 times in the past year.

**Individual choices.** The majority of individual participants chose better-than-current benefits for Vision, Doctor Care, and Dental Care (see Table 2). More than a quarter of individual participants chose lower than current levels of coverage for Complementary Medicine, Drugs, Emergency coverage, Mental Health coverage, Personal Care, Supplies, and Transportation. Participants rarely made major changes to their own health coverage selections from round 1 to round 4. However, they tended to choose a greater number of benefit categories in round 4 than in round 1 and, consequently, reduced the tier levels for the categories they included. One notable change was an increase in inclusion of mental health coverage between the initial and final rounds. Another notable change relates to diminished interest in brand name drugs. For example, as shown in Table 2, the high level, which matches

**Table 1.****PARTICIPANT CHARACTERISTICS**

Gender (%)		Pulmonary/cardiac	3
Female	69	Endocrine/gastro/renal	6
Age (mean years)	47.1	Heme/oncology	1
Family status (%)		Trauma	9
Single	60	Psychiatric	13
Single with dependents	18	Blindness/deafness	16
Couple	16	Multiple	41
Couple with dependents	6	Unreported/unclear	3
Type of community		Number of years on Medi-Cal (%)	
Urban	63	Less than 1 year	3
Suburban	16	1–5 years	24
Rural	21	6–10 years	20
Ethnicity (%)		11–20 years	30
Non-Hispanic White	67	More than 20 years	18
Hispanic	13	Doctor visits last year (%)	
African American	11	0–5 times	23
Asian	5	6–10 times	24
Native American	3	11–20 times	25
Highest educational level (%)		More than 20 times	27
Non high school grad	13	Hospitalized last year (%)	
High school grad or GED	25	Yes	31
Some college	43	Personal spending on health care (%)	
College degree	9	Less than \$100	44
Post grad degree	8	\$100–500	24
Types of disability (%)		\$500–1000	7
Neurologic	13	More than \$1000	8
Musculoskeletal	15	Don't know or no response	17
Developmental/congenital	9		

the brand name drug benefit available in the Medi-Cal program (as indicated by the gray box) was chosen by 31% of participants in the first round but by only 16% of participants in the final round.

**Group choices.** Unlike individual choices, which sometimes excluded whole benefit categories, all groups chose to include every benefit category at least at the minimal level as they designed statewide plans (Table 3). There were three categories that all of the groups considered inadequate at the lowest tier: Doctor Care, Hospital Care, and Mental Health. Half the groups picked Equipment at a level higher than currently offered. In contrast, Drugs (brand), Emergencies, and Enrollment were the categories that most often were chosen at lower benefit levels than the current Medi-Cal coverage.

**Table 2.****INDIVIDUAL MEDI-CAL PARTICIPANTS'  
COVERAGE CHOICES (N=131)**

Category	Initial choices (%)				Final choices (%)			
	No coverage	Tier 1	Tier 2	Tier 3	No coverage	Tier 1	Tier 2	Tier 3
Complementary	11	21	34*	34	8	22	42*	28
Dental care	2	7	37*	54	2	5	48*	45
Doctor care	0	2	29*	69	0	2	43*	55
Drugs (brand)	4	31	33	31*	2	28	54	16*
Drugs (generic)	9	13	77*	**	2	18	79*	**
Emergencies	5	24	70*	**	3	36	61*	**
Enrollment	**	12	32	55*	**	11	54	35*
Equipment	10	8	34*	47	8	15	38*	38
Home health	11	17	71*	**	7	22	71*	**
Hospital care	0	6	53*	41	0	7	64*	29
Mental health	15	21	21	43*	5	18	32	44*
Personal care	11	27	24	37*	4	19	38	38*
Supplies	15	24	61*	**	12	28	61*	**
Transportation	17	20	63*	**	12	35	52*	**
Vision	4	40*	56	**	5	41	55	**

\*Levels of benefit that match the benefits available in the Medi-Cal at the time this study was done.

\*\*Exercise did not have a benefit option at this tier.

**Services of greatest concern.** Eight categories elicited the most discussion when participants wanted better benefits than were currently available or feared loss of the benefits they currently had:

*Care by a Doctor.* Almost every group started by wanting to increase the number of doctors available for Medi-Cal patients. Discussion frequently included comments that there are too few doctors now accepting Medi-Cal; the time to find a doctor is too long; and insufficient choice often means poor quality of care. A characteristic comment was:

I literally went through 50 doctors in the phone book before someone said, "OK, we'll take Medi-Cal."

*Dental Care.* Like Care by a Doctor, Dental Care generated many stories of inadequate services and insufficient providers. Characteristic comments were:

**Table 3.****GROUP CHOICES FOR A BENEFIT PACKAGE FOR ALL  
MEDI-CAL BENEFICIARIES IN THE STATE (N=12 GROUPS)**

Categories	No coverage	Tier 1	Tier 2	Tier 3
Complementary	0	4	6*	2
Dental Care	0	1	7*	4
Doctor Care	0	0	7*	5
Drugs (brand)	0	6	6	0*
Drugs (generic)	0	1	11*	**
Emergencies	0	10	2*	**
Enrollment	**	1	8	3*
Equipment	0	1	5*	6
Home Health Care	0	2	10*	**
Hospital Care	0	0	11*	1
Mental Health	0	0	4	8*
Personal Care	0	1	5	6*
Supplies	0	2	10*	**
Transportation	0	3	9*	**
Vision	0	9	3	**

\*Levels of benefit that match the benefits available in the Medi-Cal at the time this study was done.

\*\*Exercise did not have a benefit option at this tier.

It'd be kind of difficult to go down on the current levels because a lot of people have [dental problems]. You know, when your mouth is in trouble, your whole body is in trouble.

I was in a car accident and got most of my teeth knocked out. I have 11 healthy teeth left. I want Level 3 so I can have [a] partial instead of just pulling out all my healthy teeth to give me full dentures.

*Equipment.* Unlike Care by a Doctor or Dental Care, not all participants used this category, and many were not inclined to prioritize it. Yet most of the CHAT sessions comprising people with differing degrees of disability, including some with profound physical limitations, provided compelling testimony along with the experience of seeing the most disabled participants functioning independently with the help of technologically advanced equipment. Participants commented:

You're gonna end up using beaucoup hours of Personal Care when a loaner chair would have done as well. You know that's the weird part about some of these regulations.

Too bad there's not a [Tier] 2½. I'd say give them a loaner, but make the replacements every five years.

*Personal Care.* Like Equipment, Personal Care is a category that was critically important to some individuals and not at all to others. Users of Personal Care (California In-Home Supportive Services) were persuasive with their colleagues about the need to maintain the current level of services; half of all groups chose Personal Care at its highest tier (current services) rather than accept the co-payments with the lower tiers. Unlike Equipment, however, Personal Care required many markers to reach the current benefit level, so the commitment that half the groups made to maintain that level reflected participants' recognition of this vital service among the disabled community. Participants commented:

It's a very well-run program; it's a low-cost program. And very few people get [the maximum] 283 hours. And 283 hours, even if it is a family care person, it's a 24-hour-a-day job, so 283 hours doesn't even cover the amount of time these people actually do [work].

The most important part is just being able to live your life [and be] as mobile as you can . . . that [is something] other people may take for granted.

*Mental Health.* Many Medi-Cal CHAT participant comments reflected having mental health diagnoses as a qualifying disability. Some comments indicated that many were not satisfied with the services now available and certainly didn't want to settle for a lesser benefit. Participants commented:

I suffer from depression; I have yet to be able to get anybody for counseling. Hardly anybody takes Medi-Cal for it, and the one place that does, they have a waiting list years long before they'll take anybody.

[Deaf patients] can't do mental health [by] writing back and forth; you need to sign [use sign language] and be able to get all the emotion out and everything.

*Enrollment.* Many participants agreed that people with adequate means should have to pay something but were skeptical of what that meant in real dollar terms. While their instinct was to keep Enrollment at its current level, compromising to a lower tier freed up many markers; consequently, 75% of the groups opted to require some people to pay a premium. One participant commented:

If they're well above the minimum, they could pay a \$10 or \$20 a month in co-pay, or pay \$3 prescription a month. It would give us back so many markers that we could use better somewhere else.

Two categories that generated some of the most discussion were Emergency Care and Brand Name Drugs. These debates occurred either at the initial placing of the markers in the group discussions or at the conclusion when participants were moving their markers around to get more categories covered.



*Emergency care.* This category was often the first to be reduced for another option. Some participants argued that it was better that unnecessary emergency room visits cost a patient \$35 (Tier 1) instead of \$5 (Tier 2) to discourage inappropriate ER use. Others countered that their access to primary care is limited and they have no choice but to use the ER. Concern about how the higher co-pay might inappropriately keep people from using the emergency department when in need was expressed in the following comment:

And if you're sick enough to call the ambulance or go into emergency, it has to take a lot. If you're thinking, I'll just lay here because I ain't got \$35, a lot of people would end up dead.

*Brand Name Drugs.* This was the most expensive category on the CHAT board, requiring 28 of the 100 markers to keep the benefit at its current level, thus eliciting much discussion about brand name and generic drugs. Because so many markers were spared by selecting the lowest tier of Brand Name Drugs, the pressure to cover other services outweighed the persuasive abilities of those participants with extensive medication needs.

You guys are missing the point. Brand-name drugs are taking up all the markers . . . you're paying for the name, that's all you paying for. . . . I mean, what's happening here?

**Weighing the priorities.** Participants' choices, as corroborated in their responses to the post-exercise questionnaire, centered on the competing priorities of the four core features of health care services that are illustrated in CHAT (Table 4).

*Range of services.* Comprehensiveness was the dominant issue for group decisions in Round 3. Responses to the CHAT questionnaire questions reinforced this concern. "Having Medi-Cal pay for as many different services as possible" was the highest ranking (21%) of eight features in the Medi-Cal program (Table 4).

But we're talking about the masses. Believe me, there are areas up there that I would like to make better for myself. But we're talking about the whole of California.

*Choice.* The issue of choice was most visible in three categories: Care by a Doctor, Drugs (brand), and Hospital Care. Care by a Doctor pertained to the need to access high-quality doctors; participants mentioned that adequate choice was their only way to ensure they would find a doctor who met their needs. The debate about brand-name drugs was mainly over the issue of formulary limitations and participants' ability to get the drug that worked best for them. For those highly dependent on certain medications, a greatly restricted formulary was difficult to accept.

But you need choices. It's all about choices. It's all about getting as many choices as you can with all the money that we have.

I don't think [that as a person using] government money, you should be able to go to one of those expensive millionaire hospitals for a broken arm.

**Table 4.**

**PREFERENCES REGARDING MEDI-CAL  
FEATURES AND SERVICE CUTS (%)**

<b>Of the following, which is most important to you in your Medi-Cal Coverage?</b>	
Having Medi-Cal pay for as many different services as possible	21
Having very small (or no) co-payments for doctor visits and medicines	15
Being able to get a doctor appointment quickly	15
Having a good selection of primary care doctors to choose from	15
Being treated with respect by my healthcare providers	13
Having a good selection of specialists to choose from	9
Having a choice of which hospital I go to	8
Having doctors available who are close to where I live	4
<b>Of the following, which two changes do you like the least?</b>	
There will be fewer doctors available for Medi-Cal patients	47
Medi-Cal will no longer pay for certain types of services	37
Medi-Cal patients must get all medical care from one local health plan	34
There will be stricter limits on the services a patient can use each month	29
Medi-Cal patients will have higher co-payments for some services	27
Those with higher income will pay a monthly fee to join Medi-Cal	16
<b>Of the following, which two changes are most acceptable to you?</b>	
Those with higher income will pay a monthly fee to join Medi-Cal	69
Medi-Cal patients must get all medical care from one local health plan	34
Medi-Cal patients will have higher co-payments for some services	32
There will be stricter limits on the services a patient can use each month	21
There will be fewer doctors available for Medi-Cal patients	15
Medi-Cal will no longer pay for certain types of services	13

*Cost-sharing.* For some participants, an increased co-payment was the factor that they mentioned as most troubling in considering a lower tier. High users of certain categories (e.g., Drugs (brand) or Supplies) were very vocal about their inability to afford co-payments because of the amount of services they use.

All of that kind of stuff [supplies] is extremely expensive, and if you're on [SSI], you'll never be able to pay for it all. A lot of the supplies you cannot reuse. You cannot [reuse] syringes; you cannot reuse incontinence supplies. You can't reuse cotton. I mean, just, you can't. So if you don't have the money what are you going to do?

*Availability.* This issue addressed concerns about the ability to access services in a timely way. While "getting a doctor's appointment quickly" ranked fairly high, "having doctors available who are close to where I live" ranked low. However, there is a thin line between what is considered available and the features of choice and range of services. Participants with special needs (for example the hearing-impaired)

mentioned particular problems in getting services that can help them, such as trouble getting interpreters with their mental health providers. Timely availability of resources was commented upon:

A year for a wheelchair, a year and a half for teeth; that is unreal and unnecessary cruelty.

## Discussion

Changes to Medicaid proposed by governors and state legislators would require many Medicaid beneficiaries to pay more for care, would reduce the scope of services, or both.<sup>2</sup> Knowledge of the priorities and concerns of disabled beneficiaries about access to providers, choice, comprehensiveness, and cost-sharing can and should inform these changes. Our findings suggest that disabled adult beneficiaries in the California Medicaid program find it most important to maintain the full range of services even if this requires instituting greater restrictions on how services are used or higher out of pocket costs. The range of disabilities and needs of individuals enrolled in the program vary so greatly that eliminating certain benefit categories while keeping others inevitably harms some subset of enrollees dramatically. The adult disabled beneficiaries in this study considered it important to avoid this and instead argued for sharing the burdens and benefits. In addition, our participants felt strongly the need to avoid reducing provider reimbursement or other cost-saving actions that might diminish the availability of physicians, dental services, and other services. On the topic of enrollment and eligibility, participants considered it more acceptable to expect eligible beneficiaries in higher ranges of income to contribute toward the cost of their Medi-Cal enrollment than to implement service reductions, although they disliked both options.

Several limitations of this project must be acknowledged. First, the CHAT exercise engages participants in a hypothetical set of choices. We do not see any obvious reason that the priorities that participants expressed in response to the options posed in this exercise would differ from the participants' priorities in a situation in which they knew their preferences would be acted upon. However, the extent to which the hypothetical nature of the exercise influenced participants' choices remains to be examined. Second, the exercise included only disabled adults of the Medi-Cal population; in any decision-making process about the overall benefits and eligibility criteria for the program the views of other groups of beneficiaries must to be taken into account. Indeed it is quite likely that the priorities of, for instance, young mothers with children and those beneficiaries who are confined to home or an institution would vary substantially from those expressed by our participants. Third, the sample was not selected randomly so caution should be exercised in generalizing our findings to the views of all non-institutionalized disabled adults enrolled in Medi-Cal. Fourth, the eligibility criteria, which required English speakers who were literate at a sixth grade reading level with cognitive ability to reason about trade-offs, excludes some segments of the population of interest. We hope to develop a Spanish version of the exercise that would circumvent the language bar-

rier. The use of additional assistants to the facilitator can, in our experience, permit inclusion of non-readers. However, the need to include individuals who are capable of reasoning is unavoidable and, we believe, justifiable since the exercise is intended to facilitate public deliberation. Certainly one could consider having surrogates stand in for those who are cognitively impaired who could argue on their behalf. Fifth, given the complexity of the Medi-Cal program, the CHAT categories and tiers could not capture all the details, exceptions, and nuances that exist, including complete actuarial precision, which were approximations based on historical costs and estimated projections and rounded to the nearest whole marker. In addition, the structural and communication barriers that greatly impede the lives of disabled individuals were not a topic within CHAT, and readers should not infer that such inaccessibility problems do not exist.

Despite these limitations, we anticipate that key findings about the need for comprehensiveness and flexibility in Medicaid programs, and about what services are most important are likely to be common concerns in the adult disabled population. It should not be inferred that this project is an endorsement of major cuts in Medicaid programs, nor that the strategies for budget cutting offered for consideration in this project, or chosen by the participants, are the best or only workable strategies to consider. Many strategies for cost containment exist besides changes in eligibility or scope of coverage, such as reducing administrative waste, promoting low cost approaches to care, reducing supply side technological excesses that fail to provide benefit, and creating integrated information technology systems in efforts to increase efficiency. We did not offer these efficiency measures among the choices for Medi-Cal beneficiaries to consider because we consider these efficiency measures non-controversial approaches worth pursuing.

While the information gathered in this project can provide valuable information about what is important to disabled adult beneficiaries of a state Medicaid program, it does not inform the debate about the degree of overall budget reduction that programs for disabled adults should absorb compared with other programs for other Medicaid eligible groups, or other state programs. This is a question of distributive fairness about how much of the burden of financial exigencies the disabled population should absorb relative to the remainder of the population. As a particularly vulnerable population, one can argue that their needs deserve high priority and that cuts in Medicaid programs should be minimized. However, competing claims of other Medicaid eligible groups and other populations outside the Medicaid program also must be weighed in balancing tight state budgets.

To what degree should beneficiaries' priorities guide policy? We would suggest that beneficiaries' choices should be one element that goes into the priority setting process along with expert opinion as policy gets made. So, for instance, if public opinion assigns low priority to a strategy that experts believe it is very cost effective, one might want to endorse its adoption into health policy despite public opinion. In this regard, various strategies put on the table for consideration in this exercise have been previously shown to have consequences for beneficiary access to care, satisfaction, and cost. These consequences must be considered in any endeavor to translate beneficiaries' views into coverage policies. While several studies have

shown that managed care is generally well received by Medicaid beneficiaries,<sup>8,9</sup> cost sharing for the Medicaid population has had mixed results. When California initiated an experiment in cost-sharing in its Medicaid program in 1972, utilization of ambulatory doctor visits declined, but after a brief lag, hospitalization rates rose for the co-payment cohort of Medicaid beneficiaries compared with the non-payment cohort, more than off-setting the savings to the state from the reduction of ambulatory services.<sup>10</sup> A questionnaire of beneficiaries at that time indicated that households with the greatest medical need reported the greatest reduction in available care.<sup>11</sup> These findings indicate how crucial it is to design co-payment schemes that are adjusted to take medical need and level of poverty into account, for instance having co-payments end or decline after a maximum out of pocket amount has been reached. Co-payments on prescriptions may be a more workable strategy than capping the permissible number of prescriptions, but the levels of co-payments that have been studied in the past have been much lower than those currently under consideration.<sup>12</sup>

The CHAT process used in this project is based on principles of deliberative democratic decision making and on the idea that one can learn a great deal about how people prioritize services by having those services compete within a finite budget.<sup>13–15</sup> The process provides a window onto the thought processes of individuals and groups as they struggle to balance their own needs and those of the larger population. To the extent that every state faces pressures to limit Medicaid costs the exercise may be of value to many of them and could easily be adapted for this purpose by incorporating the benefit options and actuarial costs relevant to their covered populations. Some may find the length of the exercise prohibitive and could abbreviate some of the rounds if necessary, although in doing so the more prudent thinking that is gained as participants learn from each other's medical experiences would be curtailed.

Of course, agreeing to make trade-offs during the CHAT process is not the same as accepting those cutbacks in real life. Some participants were well aware of the danger that the CHAT results could pose: that policymakers would mistakenly interpret their decisions as *acceptance* of cutbacks. Others saw this exercise as a way to openly and honestly tell policymakers what services are most important to them and why. Members of both groups, the suspicious and the eager, wanted to convey their stories and concerns.

From the perspective of participants in this project, there is no low-hanging fruit in Medi-Cal. Every service category has its advocate; every higher level tier has its promoter. While acknowledging that misuse and inefficiency exist in the system, most people were concerned that legislative decisions to cut Medi-Cal would make life considerably harder for them than it is now. Thus, the results described in this report should be interpreted in the light that the participants intended. As one commented:

Well you know most of the Medi-Cal people are poor to begin with, so it seems to balance the budget on the backs of the poorest of people who are on Medi-Cal doesn't make any sense to me.

Disabled adult beneficiaries in the California Medicaid program find it most important to maintain the full range of services even if this requires instituting greater restrictions on how services are used or higher out of pocket costs for those who can afford them. From their perspective, access to a large pool of providers takes precedence over unrestricted pharmacy benefits. These findings may be of value to Medicaid programs around the U.S. as they struggle to design affordable benefit packages for disabled beneficiaries.

## Acknowledgments

This work was funded by grants from the California HealthCare Foundation and Sutter Community Hospitals-Sacramento. The authors wish to acknowledge the advice of the Medi-Cal CHAT Advisory Committee members: Amerish Bera, M.D.; Sharon Bishop; Farra Bracht; Ellen Dunn-Malhotra; Robin Krause; Gail Meeks; John Miller; Leah Morris; Chris Perrone; Brenda Premo; Miko Sawamura; Patricia Yeager.

The opinions expressed here are those of the authors and are not a reflection of the policies of the National Institutes of Health or the U.S. Department of Health and Human Services.

## Appendix: Medi-Cal CHAT Categories, Definitions, Benefit Levels, and Number of Markers (in Parentheses)

**1. Complementary:** Out-patient services such as speech, physical and occupational therapy, podiatry (foot care), acupuncture, and chiropractic.

*Tier 1:* (1) No more than one visit each month to any of the services listed. You pay \$3 for each visit. For most services, your doctor or Medi-Cal must approve in advance.

*Tier 2:* (1+1) No more than two visits each month to any of the services listed. You pay \$1 for each visit. For most services, your doctor or Medi-Cal must approve in advance. (Current)<sup>a</sup>

*Tier 3:* (1+1+1) Same visits as Tier 2, but they do not need to be “medically necessary” as long as they help you function better. Approval by doctor or Medi-Cal is not necessary.

**2. Dental Care:** Pays for the care of your teeth.

*Tier 1:* (2) Provides the same services now available with Medi-Cal, but it takes longer to find a dentist and get appointments. You pay \$5 for each visit and have a maximum coverage of \$1,000 each year.

*Tier 2:* (2+1) Provides the same services now available with Medi-Cal. You have no copayment for visits, and the maximum coverage is \$3,000 each year. (Current)

<sup>a</sup>(Current)—Indicates that the Medi-Cal Program currently offers this level of coverage.

*Tier 3: (2+1+1)* Provides the same services, but many more dentists are available so appointments are easier to get. You have no copayment for visits, and there is no maximum coverage each year.

**3. Doctor Care:** Primary care and specialists for treating routine and complex medical problems. Includes tests, X-rays, and scans for evaluating problems, as well as procedures and surgery.

*Tier 1: (6)* Medi-Cal decides to reduce payments to doctors. Though you may go to any doctor who accepts Medi-Cal, many will no longer take Medi-Cal patients. It may take you six to eight months to find a doctor.

*Tier 2: (6+3)* You may go to any doctor who accepts Medi-Cal, but finding a primary doctor is often difficult, and specialists are sometimes not available. It may take you three to six months to get a doctor's appointment. (Current)

*Tier 3: (6+3+3)* With better payment, many doctors will accept Medi-Cal, so you have many more to choose from and can change doctors easily. It may take only a few weeks to get a routine appointment.

**4. Drugs (brand):** Pays for brand-name drugs on the Medi-Cal formulary (approved list). These brand-name drugs are newer medications that are copyrighted. They are often much more expensive than generic medicines.

*Tier 1: (14)* The formulary will be very limited, and many brand-name drugs will no longer be covered (especially new, expensive drugs). You have a \$5 copayment for each. If there is a less costly generic drug available, your doctor cannot order the brand-name version.

*Tier 2: (14+7)* The formulary will be somewhat limited, and some brand-name drugs will no longer be covered. You have a \$3 copayment for each. But your doctor may order brand-name drugs even if the generic drug is available.

*Tier 3: (14+7+5)* The formulary is no different than it is currently. Your doctor does not have to order generic drugs to substitute for brand-name drugs. You have a \$1 copayment for each. Your doctor must get approval to prescribe a non-formulary drug. (Current)

**5. Drugs (generic):** Pays for generic drugs on the Medi-Cal formulary (approved list). These medicines are made the same way as brand-name drugs when their copyright expires. Generics are usually much less expensive than brand-name drugs.

*Tier 1: (7)* The formulary for generic drugs will be quite limited, so some drugs will not be covered. Your copayment is \$3 for each generic drug you use each month.

*Tier 2: (7+2)* The formulary for generic drugs is *not* limited. Also, if Medi-Cal approves, your doctor may prescribe a generic drug not on the formulary. Your copayment is \$1 for each generic drug you use each month. (Current)

**6. Emergencies:** The use of hospital emergency rooms (ER).

*Tier 1: (1)* Pays for emergency room services at the nearest hospital. If the visit is not an emergency, you pay \$35.

*Tier 2: (1+1)* Pays for emergency room services at the nearest hospital. If the visit is not an emergency, you pay \$5. (Current)



**7. Enrollment:** (This is a *required* category.) This sets the rules for Medi-Cal enrollment based on income and property. There are currently about 750,000 disabled California residents receiving Medi-Cal services.

*Tier 1:* (4) Medi-Cal changes the rules for income and property. With this change, one out of five disabled people (those above the minimum income) will have to pay for some of their medical visits or must pay a monthly fee to enroll.

*Tier 2:* (4+6) Medi-Cal changes the rules for income and property. With this change, one out of ten disabled people (those well above the minimum income) will have to pay for some of their medical visits or must pay a monthly fee to enroll.

*Tier 3:* (4+6+6) Medi-Cal rules stay the same, so this does not affect those who enroll in the program. (Current)

**8. Equipment:** Includes items such as wheelchairs, breathing equipment, and assistive devices that prevent or improve a functional limitation. Must be ordered by a doctor.

*Tier 1:* (1) Equipment must be approved by Medi-Cal, and models are limited. Repair time is slow, and you pay half the cost of repairs. "Loaners" are not covered. Replacements every seven years.

*Tier 2:* (1+1) Medi-Cal approval is required for some of the equipment. When repairs are needed, "loaners" are not covered. Replacements every five years. (Current)

*Tier 3:* (1+1+1) All equipment must be approved, but specialists will advise you and equipment can be customized to your needs. "Loaners" are available when needed. Replacements every three years.

**9. Home Health Care:** Part-time skilled care in the home on a short-term basis by nurses, aides, and others, usually after hospital care. Used to prevent decline in health status and maintain highest level of function.

*Tier 1:* (1) All services must be approved in advance. Aide services are limited to a few hours each day. Total number of hours cannot exceed five per week for no more than a couple of weeks.

*Tier 2:* (1+1) All services must be approved in advance. There is no stated limit on the number of visits each week or number of weeks of service. (Current)

**10. Hospital Care:** Pays for in-patient hospital stays (including mental illness), out-patient services, and short-term physical rehabilitation in a skilled nursing home.

*Tier 1:* (12) You have no choice of which hospital or skilled facility you go to.

*Tier 2:* (12+2) You have some choice of private or public hospitals or skilled facilities. (Current)

*Tier 3:* (12+2+2) You can go to any hospital or skilled facility you choose.

**11. Mental Health:** Out-patient mental health therapy; may include drug or alcohol treatment programs.



*Tier 1:* (7) Pays only for the most severe mental health illnesses such as bipolar disorder, severe depression, and anorexia. You have a \$3 copayment each visit. Does not cover drug or alcohol treatment.

*Tier 2:* (7+4) Besides the severe illnesses, also covers many other mental health problems. For less severe problems, limit is two visits per month with a \$2 copayment. Also covers drug and alcohol treatment.

*Tier 3:* (7+4+1) Besides the severe illnesses, also covers many other mental health problems. Amount of service depends on client needs, but no limit. Average copayment is \$1 per visit. Also covers drug and alcohol treatment. (Current)

**12. Personal Care:** In-home personal care services (California In-Home Supportive Services, or IHSS) for those with a disability lasting more than 12 months. Medi-Cal approves an average of 110 hours each month (maximum is 283 hours).

*Tier 1:* (7) If you need more than 110 hours each month, you pay 30 % of the cost of all approved hours above 110. This will affect about one-third of the users of Personal Care.

*Tier 2:* (7+3) If you need more than 110 hours each month, you pay 10 % of the cost of all approved hours above 110. This will affect about one-third of the users of Personal Care.

*Tier 3:* (7+3+2) Provides personal care services for up to 283 hours each month, with approval. There are no copayments. (Current)

**13. Supplies:** Disposable medical equipment and supplies for in-home use (such as syringes, catheters, urinary incontinence protection, etc.).

*Tier 1:* (1) Pays for supplies that are prescribed by a doctor. If not on the supply formulary, approval is needed. Only pays for \$100 of supplies each month.

*Tier 2:* (1+1) Same as Tier 1, except that there is no limit to the amount that can be purchased (but there is a \$165 monthly limit for incontinence supplies). (Current)

**14. Transportation:** For those whose condition prevents the use of private vehicle or public transportation, this provides rides for approved medical appointments. Also provides an ambulance in an emergency.

*Tier 1:* (1) For rides to medical appointments, the copayment is \$2 for each ride. Pays for four one-way trips each month. Pays for an ambulance in an emergency. If the doctor says it was *not* a real emergency, you pay \$35.

*Tier 2:* (1+1) For rides to medical appointments, there is no copayment and no limit on the number of rides each month. Also pays for an ambulance for emergencies, without a copayment. (Current)

**15. Vision:** Eye exams and glasses from an optometrist.

*Tier 1:* (1) You get an eye exam and glasses every two years, if needed. This entitles you to basic lenses and frames. Contact lenses are provided only if medically necessary. (Current)

*Tier 2:* (1+1) You get an eye exam and two pairs of glasses or contact lenses every year, if needed.

## Notes

1. Pear R. Health secretary calls for Medicaid changes. *New York Times*. 2005 Feb 2, A12.
2. Pear R. States proposing sweeping change to trim Medicaid. *New York Times*. 2005 May 9, A1.
3. California Healthcare Foundation. Medi-Cal facts and figures: a look at California's Medicaid program. Oakland, CA: California HealthCare Foundation, 2004 Jan.
4. Danis M, Ginsberg M, Goold S. Preparing employees to participate in the design of their health insurance benefits. *J Gen Intern Med*. 2004; 19 Supplement 1:197.
5. Goold SD, Green SA, Biddle AK. Will insured citizens give up benefit coverage to include the uninsured? *J Gen Intern Med*. 2004 Aug;19(8):868–74.
6. Danis M, Biddle AK, Goold SD. Enrollees choose priorities for Medicare. *The Gerontologist*. 2004 Feb;44(1):58–67.
7. Danis M, Biddle AK, Goold S. Insurance benefit preferences of the low-income uninsured. *J Gen Intern Med*. 2002 Feb; 17(2):125–33.
8. Sisk JE, Gorman SA, Reisinger AL, et al. Evaluation of Medicaid managed care. Satisfaction, access, and use. *JAMA*. 1996 Jul 3;276(1):50–5.
9. Backus LI, Bindman AB. Low-income Californians' experience with health insurance and managed care. *J Health Care Poor Underserved*. 2001 Nov;12(4):446–60.
10. Roemer MI, Hopkins CE, Carr L, et al. Copayments for ambulatory care: penny-wise and pound-foolish. *Med Care*. 1975 Jun;13(6):457–66.
11. Hopkins CE, Roemer MI, Proctor DM, et al. Cost-sharing and prior authorization effects on Medicaid services in California: part I. The beneficiaries' reactions. *Med Care*. 1975 Jul;13(7):582–94.
12. Sumera I SB, Avorn J, Ross-Degnan D, et al. Payment restrictions for prescription drugs under Medicaid. Effects on therapy, cost, and equity. *New Engl J Med*. 1987 Aug;317(9):550–6.
13. Gutmann A, Thompson A. *Democracy and disagreement*. Cambridge, MA: The Belknap Press of Harvard University Press, 1996.
14. Fleck, LM. Just health care rationing: a democratic decision-making approach. *Univ of PA Law Rev*. 1992 May;140(5):1597–636
15. Goold SD, Biddle SK, Klipp G, et al. Choosing Healthplans All Together: a deliberative exercise for allocating limited health care resources. *J Health Polit Policy Law*. 2005 Aug;30(4):563–601.